What is a CTR?

“Certified Tumor Registrar”

- We also collect data on reportable benign tumors as well as cancer
- We’re most commonly referred to as “Cancer Registrars”

Overview

- What is a CTR
- Cancer Registries & Process
- Knowledge base of a CTR
- What IS an Abstract
- What’S IN an Abstract
  - How do CTRs collect information
  - Who Makes the Rules
  - Standard Setters
  - Coding Applications
  - Patient Follow-up
  - Confidentiality
  - Education Requirements
  - Where do CTRs work
  - Characteristics of a CTR
What is a CTR?

- CTRs are trained to collect data on all types of cancer diagnosed and/or treated within an institution, or other defined population.
- CTR's report the resulting cancer statistics to various health care agencies and state or national cancer registries.

Responsibilities of Cancer Registrars

- Collect timely, accurate, and complete cancer data
- Develop expertise on all types of cancer
- Summarize patient’s disease, from diagnosis to death in an “abstract”
- Provide support for cancer programs, and ensure compliance of reporting standards
- Collect cancer/tumor data from a variety of sources.
- Provide data for studies, create reports to illustrate data and report Cancer Statistics to various health care agencies.
- Some CTRs organize Cancer Conferences at (ACoS/CoC) hospitals

What is a Cancer Registry

- An Information system designed for cancer data
  - Collection
  - Storage
  - Management
  - Analysis
- A type of disease registry
Purpose of a Cancer Registry

- Establish and maintain a cancer incidence reporting system
- Serve as an information resource for cancer research
- Provide information to assist public health officials and agencies

Types of Cancer Registries

**Hospital registries - Incidence-based**
- Improvement of patient care
- Professional education
- Administrative information
- Clinical research

**State registries - Population-based**
- Cancer prevention
- Early detection
- Determination of cancer rates and trends
- Assess patterns of care and outcomes
- Research
- Evaluation of control efforts

NCRA “Introduction to the CANCER REGISTRY”
NCRA “An Introduction to the Cancer Registry”
Cancer Registration Process

- A continual, systematic collection of data on the occurrence and characteristics of reportable malignancies and tumors.

CTR Knowledge

CTR Required Knowledge Base

- Medical Terminology
- Anatomy and Physiology
- Cancer Disease Characteristics
- Understanding of Clinical Practice & Evidence based Guidelines
- Cancer Data Abstracting
- Cancer Staging Systems
**CTR Required Knowledge Base**

- Cancer Registry Procedures
- Cancer Registry Database Management
- Statistics and Epidemiology
- Survival Analysis
- Cancer Program Management*

*Optional – Further Edu

---

**What IS an Abstract?**

- "A record that contains information about each patient's tumor from the time of diagnosis and continuing throughout his or her life" NCRA

---

**The Cancer Registry Abstract**

- "A record that contains information about each patient’s tumor from the time of diagnosis and continuing throughout his or her life" NCRA
What Information is Collected “IN” an Abstract?
And how is it collected

What’s “In” an Abstract

- Patient Demographics
  - Name
  - DOB
  - Address at Diagnosis
  - Gender, Race, Ethnicity
  - Marital status, Place of Birth
  - Insurance provider
  - Occupation

Admission Information

- Date of first contact with facility
- Admission Dates – Inpatient/Outpatient
- Patient Referred from/Referred to
- Physicians & Specialists managing patient
- Class of Case
  - Analytic – diagnosed or treated for cancer at that facility, included in hospital data analysis
  - Non-analytic – seen for some other reason, no cancer dx or treatment provided by the facility, excluded from hospital data analysis
What’s “In” an Abstract

- **Patient History & Comorbidities**
  - Physical findings, relevant presenting symptoms
  - Other conditions, disease which could affect treatment decisions or outcomes (Diabetes, COPD, heart disease, etc.)
  - Height, weight, tobacco & alcohol use
  - Patient family history and patient history of previous cancers

- **Diagnostic Workup**
  - Imaging
  - Ultrasounds
  - Endoscopy
  - Biopsies
  - Tumor Markers
  - Labs/other
  - Must document
    - Dates, Procedures & Findings

- **Tumor Information**
  - Date of Diagnosis
  - Type of Diagnostic Confirmation
  - Primary Site/Laterality
  - Histology Type/Behavior/Grade
  - Tumor size, or invasion within the organ or contiguous extension beyond
  - Prognostic Indicators
  - Extent of disease at diagnosis
What’s “In” an Abstract

Stage of Disease at Diagnosis
- AJCC TNM Staging
  - Pretreatment-Clinical
  - Postsurgical-Pathologic
  - Neoadjuvant
- Collaborative Staging
  - Based on clinical and pathologic features combined
- SEER Summary Stage 2000
  - In situ, Local, Regional, Regional & Post(-) LNs, Distant

Each has different set of rules

What’s “In” an Abstract

Treatment
- Surgery
  - Procedure, surgical margins
  - Lymph nodes examined
  - Surgical Observations
- Chemotherapy
  - Name of agents, doses, dates, Clinical trial info
- Radiation therapy
  - RT Modalities (External beam, brachytherapy, IMRT, etc.)
  - Doses (cGy, etc.)
  - Volume - Breast, or breast & lymph nodes, etc.

What’s “In” an Abstract

Treatment
- Hormonal therapy
- Immunotherapy
- Other therapy
- Document agents, dates, contraindications, complications
  - Or patient refusal
How We Collect Information

- Read medical record(s)
- From multiple sources & databases
- May contact other physician offices, hospitals, pathology labs, oncology and radiation offices, surgery centers, etc.
- Information is collected and documented in both a textural narrative and “coded” using standardized coding applications.
- The abstract is the basic foundation for all registry operations.

Standard Setters

- California Cancer Registry
- NAACCR
- SEER
- NCI
- NPCR
- CDC
- ACoS/CoC (FORDS)

Organizations Who Govern Cancer Data Collection

- National Program of Cancer Registries (NPCR) at the Center for Disease Control (CDC)
  - Governs and supports registries in 45 states, the District of Columbia, and three territories, representing 96% of the U.S. population

- Surveillance Epidemiology and End Results program (SEER) at the National Cancer Institute
  - Source of cancer incidence and survival data from population-based cancer registries covering approximately 28% of the population

- Together, CDC’s NPCR and NCI’s SEER collect data for the entire U.S.
Organizations Who Govern Cancer Data Collection

- **North American Association of Central Cancer Registries (NAACCR)**
  - Develops and promotes uniform data standards for cancer registration, provides education and training, certifies population based registries, aggregates and publishes data from central registries.

- **California Cancer Registry (CCR)**
  - Sets rules for data collection requirements within California and follows coding structures and requirements from NPCR and NAACCR.

Organizations Who Govern Cancer Data Collection

- **American College of Surgeons Commission on Cancer (ACoS/CoC)**
  - Created the first set of standardized data set items and developed coding rules.
  - Create patient care guidelines for cancer centers.
  - For consistent patient cancer care.
  - Participating hospitals must meet specific criteria.
  - CTRs use CoC/FORDS coding rules for their hospitals.
  - CTRs must collect data to meet all requirements set by the various standard setting organizations.

Abstracting Coding Manuals & Applications
Coding Manuals & Applications

- CTR’s must use various coding applications to code different portions of the abstract.

- These coding applications are necessary so data is entered accurately and just as important, standardized across all registries.

California Cancer Reporting System Standards
Volume 1: Abstracting and Coding Procedures for Hospitals

- CCR’s online abstracting resource for data collection in California.

- CA has different data collection requirements compared to other states.

- The CCR maintains and updates as needed based on Annual Data changes from SEER, FORDS, NAACCR and NPCR.

Facility Oncology Registry Data Standards (FORDS)

- Registry standards/instructions for ACoS/CoC hospitals.

- Instructions direct:
  - How to complete each field
  - Required case types
  - Code definitions
  - Additional data fields required for CoC hospitals.

- CoC hospitals must incorporate the FORDs rules along with the CCR rules.
International Classification of Disease for Oncology (ICD-O-3)

- Primary site (Topography)
- Histology (cell type)
- Behavior (benign, in situ, invasive)
- Grade (tumor cell differentiation)

Example
- Central breast = C50.1
- Poorly differentiated infiltrating ductal carcinoma = 8500/3

Multiple Primary and Coding Histology Rules

- Consistent and Standardized coding to...
  - Determine number of primary sites
    - Two or more tumors in same primary site
  - Designation of combination histology
    - Two or more histologies in same tumor

- 9 Site Specific Rule sets for
  - lung, breast, colon, melanoma of the skin, head and neck, kidney, renal pelvis/ureter/bladder, and malignant brain cancers
  - Separate rules for malignant solid tumors in all other sites

Hematopoietic Database

- Hematopoietic and lymphoid neoplasms
  - Leukemia
  - Lymphoma
  - Blood disorders

- Accurate reporting
  - One primary or two primaries
  - Histology coding
American Joint Committee on Cancer (AJCC) Staging Manual

- TNM tumor staging
  - Tumor
  - Nodes
  - Metastasis
- Each cancer site has its own rules
- No Staging schema for Brain, CNS and hematopoietic and Lymphoid neoplasms.

Collaborative Stage Data Collection System

- Tumor size
  - Tumor extension and evaluation
- Lymph nodes and evaluation
  - Number examined
  - Number positive
- Distant metastasis and evaluation
- Site-specific factors 1-25

Surveillance, Epidemiology & End Results (SEER) Summary Stage 2000

- Categorizes how far tumor has spread
  - In situ
  - Localized
  - Regional
  - Regional with LNs
  - Distant
- Applicable to All malignant primary sites
Patient Follow-up

Follow-up Provides
- Patient current address
- Other contacts for patient
- Update on current managing physicians
  - Patient Vital Status
  - Current cancer status
    - Free of cancer
    - Recurrent disease
- Additional treatment(s)
- New type of cancer

Patient Follow-up Process
- Performed annually on every patient
- Yearly or Monthly patient list generated
  - Follow-up list compared to various sources
  - Hospital admissions
  - Outpatient and clinic encounters
  - Physician or Patient phone calls or letters
  - Other hospital registries or facility contacts
  - If needed, contact made with patient designated family or friends
  - Search Obituaries and State death indices
Confidentiality

The Cancer Registrar's Role

Confidentiality & Cancer Registry

- Cancer data is highly confidential with laws & rules which regulate its use.
- Cancer registries must submit data for state and national reporting per established laws.
- HIPAA allows cancer registries to share and exchange information with other hospitals, registries or physicians diagnosing or treating a shared patient.

Confidentiality-A CTR's Role

- Data is encrypted when it's sent outside the registry.
- Registrars strip identifying information before releasing data to researchers.
- Protect patient identifiers in Cancer Conferences, studies and the annual follow-up process.
CTR Education & Certification Requirements

- In the past CTRs were trained primarily on the job.
- Today many formal education programs exist.
- Certification exam offered twice annually.

CTR Education & Certification Requirements

- Multiple eligibility route/options available.
- Minimum requirement AA degree plus Eligibility requirements to take exam.
Eligibility Routes/ Route A - Path 1

Education
Successful completion of an Associate's Degree in Cancer Registry Management (CRM) OR Cancer Information Management (CIM) from an NCRA-accredited Program

Experience
Clinical Practicum
Successful completion of a 160-hour clinical practicum in a CTR-staffed cancer registry

Exam
CTR Exam
4.5 hrs.
250 Questions
Multiple choice

The AA degree: Complete AA degree in CRM or CRM → Complete Practicum → Pass Exam

Eligibility Routes/ Route A - Path 2

Education
Successful completion of a minimum of any Associate's Degree in any field or the equivalent (60 college-level credits) and →

Education
Successful completion of a Certificate in CRM or CIM from an NCRA-accredited Program and →

Experience / Exam
160-hour clinical practicum in a CTR-staffed cancer registry Successfully Pass CTR Exam

Certificate Program
Student already possess a college degree (AA or BA, etc.) → Complete Certificate program → Complete Practicum → Pass Exam

Eligibility Routes / Route B

Education
Successful completion of a minimum of any Associate's Degree in any field or the equivalent (60 college-level credits) and →

Education
Two college Semesters Human Anatomy & Human Physiology and →

Experience / Exam
1,950 hours (equal to one year full time) experience in the cancer registry field Successfully Pass the CTR Exam

AA degree → Take A&P → Work Full Time x 1 year in a cancer registry → Pass Exam
Maintaining your CTR

- Requires completion of 20 cancer related education CEs every 24 months
- National Cancer Registrar's Association
  - The NCRA is the national organization who manages credentialing, offers education, lobbies, and supports the cancer registry profession.

Where Do CTR's Work

- Most Cancer Registrars work for hospitals
- Radiation or Medical Oncology Centers
- State Central or Regional registries
- Standard Setting Organizations SEER, NAACCR, NPCR, the CoC, or AJCC
- Government Agencies
- Research & Pharmaceutical Companies
- Cancer Registry Software Vendors
- Cancer Registry Consulting and Contracting Firms
- Self Employed Contractors
Summary Cancer Data Collection

- There are multiple organizations and coding applications which must be used and observed to collect cancer data.
- Abstract data is a combination of textual and coded information which must be complete and accurate.
- Abstract data is used in facility analysis, treatment analysis, quality of patient care studies and survival analysis.

Information Collected in an Abstract

- Demographics
- Pertinent medical history including previous tumors
- Physical exam findings
- Diagnostic workup
- Primary tumor/cancer site
- Morphology / Histology
- Cancer staging
- Treatment- surgery/chemo/radiation ,etc.
- Lifetime patient follow-up
Summary - Cancer Abstract

- The cancer registry process is a continual, systematic collection of data on the occurrence and characteristics of reportable malignancies and tumors.

- “A record that contains information about each patient’s tumor from the time of diagnosis and continuing throughout his or her life”

CTR Credential

- Demonstrates a requisite medical and scientific knowledge base and professional competence needed for cancer data collection

Characteristics of a CTR

- Dedicated
- Enthusiastic
- Self-motivated
- Detail-oriented
- Have medical and scientific knowledge
- Enjoy working behind the scenes
- Greatest satisfaction is contributing to the knowledge of cancer to improve patient care.
What is a CTR?

- CTR’s are data management experts who collect tumor & cancer data from a variety of sources treated within an institution or other defined population and report the resulting cancer statistics to various health care agencies.

- CTRs bridge the information gap by capturing a complete summary of a patient’s disease from diagnosis to death.

Acknowledgements

- National Cancer Registrars Association

- “An Introduction to the Cancer Registry”